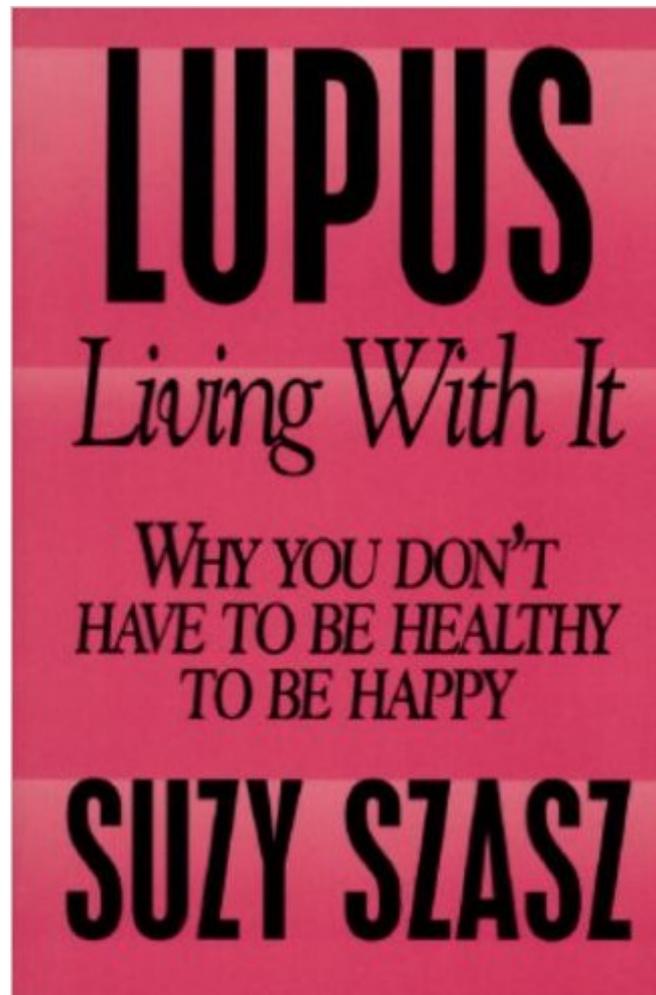


The book was found

Lupus



Synopsis

This work is a courageous account of living with a chronic illness, a powerful lesson in self-determination, and a personal declaration of independence.

Book Information

Paperback: 243 pages

Publisher: Prometheus Books; 1 edition (October 1, 1995)

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Average Customer Review: 3.3 out of 5 stars [See all reviews](#) (7 customer reviews)

Best Sellers Rank: #873,759 in Books (See Top 100 in Books) #23 in [Books > Health, Fitness & Dieting > Diseases & Physical Ailments > Lupus](#) #50 in [Books > Health, Fitness & Dieting > Diseases & Physical Ailments > Rheumatic Diseases](#) #115 in [Books > Health, Fitness & Dieting > Diseases & Physical Ailments > Genetic](#)

Customer Reviews

I think it took a lot of courage for Ms. Szasz to write this book. It really delves into her past personal life and shows a person how to try and deal with life on a day to day basis. Having a chronic illness is no piece of cake and to me when I read about her getting up and going to work everyday and trying to live as normal a life as possible, it encouraged me to do the same. Some may say that it gives readers a sense that they will go through exactly what the author has, but if the patient has been properly educated by their physician that shouldn't happen. By the time I finished her book, like one other stated I felt that I just said goodbye to a close friend and also 'Thank You'. Thank you, not only for showing me that you can live a normal life, but in all honesty, you should without ever lowering your expectations or changing your dreams.

Ms. Szasz' journey with lupus is decidedly atypical, and could unduly alarm many who suffer from lupus. Yet, her pluckiness and approach to her illness can help the faint of heart advocate for themselves in dealing with their illness and with their physicians. Although I often felt that her relational functionings left something to be desired, and felt this was a book I wouldn't want to own, in the end, I had formed an affection for her. I often remember and savor the lessons I learned and

her wry wit. Finishing the book was like saying goodbye to an enigmatic friend who has lived life with bravery and zest, and who taught you a few flourishes along the way..This is not a book which details symptoms, diagnosis and treatment of lupus, but rather, as the author states, a book about what it is like to live daily with a chronic illness whose effects are not readily apparent nor understood by those who surround its target.

I loved the title of this book but was disappointed in the book itself. The author was diagnosed with Lupus at thirteen and is on megadoses of Prednisone (up to 160 mg/day!) from then on despite being given other immunosuppressants as well. She is a classic over-achiever, expecting herself to get straight A's right up to getting several masters degrees and a doctorate, and often carrying more than a normal course load, despite her disease. She takes a minimal amount of time off when her disease forces her to, but goes right back to work, sometimes even as she lies in bed. She, like many of us with chronic diseases, sees hospitalization as the ultimate defeat. I kept waiting for her to realize that she needed to slow down and take it easier, but she never does! I wonder how much of her hyperness is due to the prednisone, she seems totally unable to rest or relax. At the time she wrote the book she is 32 and has severe osteoporosis that causes ribs to crack and vertebrae to collapse if she moves too sharply. Her height has dropped from 4'10" to 4'7" and she has to wear a back brace, and has muscle weakness from the steroids. but she is still working as a research librarian and writing books in her spare time. This is a somewhat scary book for those of us on long-term prednisone, a real warning of the price we may pay in the long term. However, her courage in facing her difficulties and pursuing her goals despite them, as well as her frank advice on selecting a doctor and dealing with the medical establishment, gives the book some value. Her father being a doctor and her own research bent, mean she is as knowledgeable if not more knowledgeable about lupus than her doctors, and takes a strong role in determining her own treatment.

This book is highly recommendable for anyone who has to contend with disease and physicians, which is most of us. Suzy Szasz, daughter of the brilliant psychiatrist-philosopher Thomas Szasz, contends with the vicissitudes of health and life intelligently and gracefully. Despite her debilitating condition she isn't debilitated: she doesn't become the obligatory American victim. Some readers will resent her relentless stand against personal adversity since it tilts against the modern American spirit. Others will admire her and take away the unspoken lessons of her quiet courage. You will find no whining in this book and no scapegoating. There is an implicit warning, though: you had better be

armed with knowledge before you hand yourself over to the doctors. Your interests may not be identical to theirs

I have read this book over 6 times and I always catch something new. Thanks to this book it helped me cope a little with the medication my doctor has put me on. This is a wonderful read and very informative.

Of all the lupus books I have read (and I have read many). this was the most discouraging of all. I admired Ms. Szasz's tenacity but I found the course of her illness to be terrifying. Her relationships with others sent me into depression. Over the course of time, I have found that books by rheumatologists with short anecdotes about patients serve my needs better than stories of a single patient's journey.

I, too, was fascinated with the author's journey and disturbed by her relationships with others. She is judgemental and critical of those upon whom she relies. And she relies on them very, very much. Obviously she comes from wealth and means, never struggling with the pain and difficulties that come from financial ruin, dealing with Social Security Disability, poverty and working, even while very sick, when your very survival depends upon it. Not all of us have Wealthy Doctor Daddy to rescue us whenever we are in trouble. Having said that, I relate to and admire her chutzpah in dealing with her doctors, her efforts to be informed and educated about her illness and her willingness to take responsibility for managing her illness. Her story is most useful in showing persons with chronic illness how to manage their care and advocate for themselves. It is a compelling story, nonetheless!

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